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Adopting the sensemaking perspective for chronic disease self-management

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ABSTRACT

Background: Self-monitoring is an integral component of many chronic diseases; however few theoretical frameworks address how individuals understand self-monitoring data and use it to guide self-management.
Purpose: To articulate a theoretical framework of sensemaking in diabetes self-management that integrates existing scholarship with empirical data.
Methods: The proposed framework is grounded in theories of sensemaking adopted from organizational behavior, education, and human–computer interaction. To empirically validate the framework the researchers reviewed and analyzed reports on qualitative studies of diabetes self-management practices published in peer-reviewed journals from 2000 to 2015.
Results: The proposed framework distinguishes between sensemaking and habitual modes of self-management and identifies three essential sensemaking activities: perception of new information related to health and wellness, development of inferences that inform selection of actions, and carrying out daily activities in response to new information. The analysis of qualitative findings from 50 published reports provided ample empirical evidence for the proposed framework; however, it also identified a number of barriers to engaging in sensemaking in diabetes self-management.
Conclusions: The proposed framework suggests new directions for research in diabetes self-management and for design of new informatics interventions for data-driven self-management.

1. Introduction

With the growing prevalence of chronic diseases, more individuals need to proactively engage in self-management of their health [1]. For many chronic conditions such as asthma, hypertension, and diabetes, self-monitoring has long been an integral and critical component of self-management [2–4]. Specifically in the case of diabetes, higher frequency of self-monitoring of blood glucose levels has been associated with better glycemic control and improved clinical outcomes [5–7]. Novel technologies provide an unprecedented opportunity to capture and monitor data related to health and wellness. Current glucose monitoring devices produce high accuracy readings with smaller blood drop volumes; this reduces the pain associated with daily testing of blood glucose, and enables more frequent testing. Individuals around the world already use mobile and wearable devices to track their diets, physical activity, sleep, and stress levels. The activists of the Quantified Self movement—a rapidly growing group of individuals who extensively monitor various aspects of their lives [8]—are only the tip of the self-monitoring iceberg, and are likely to be followed by others as the price tag for data capture technologies continues to decrease. This explosion of data has enabled the *big data* movement setting forth a research agenda for utilizing data of high volume, velocity, and variety to enable discovery [9].

Yet, despite the general enthusiasm for big data in health care in general, and health self-management in particular, there remains considerable skepticism regarding ability of individuals and their providers to make sense of the data collected through self-monitoring, and translate it into improvements in self-management behaviors [10]. Researchers have repeatedly raised concerns in regards to individuals' ability to interpret daily blood glucose readings and translate them into action [11]. With increased data available to individuals, these concerns are likely to amplify, unless these new data are coupled with tools for analysis and discovery.

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Tools for facilitating self-management are most successful when their design is grounded in cognitive and behavioral theories. A recent systematic review of informatics interventions suggested Social Cognitive Theory [12,13], Self-Determination Theory [14], Theory of Planned Behavior [15], and Transtheoretical Model of behavior change [16] among the most popular and influential in guiding the design of interventions for self-management [17]. However, most of these theories focus on factors that motivate and regulate individuals' behaviors and on the psychosocial determinants of these behaviors; few explicitly examine how individuals make sense of their disease, learn from past experiences, interpret new information and developmental models to inform their future choices. Perhaps as a result, the vast majority of technological interventions for diabetes self-management continue to focus on impacting behaviors, rather than on helping individuals make sense of and learn from collected personal data.

In this paper we discuss a way of conceptualizing how individuals make sense of their chronic disease using self-monitoring data through the theoretical lens of sensemaking. Sensemaking as a method of inquiry has deep roots in organizational behavior [18], education [19], and human–computer interaction [20]. Sensemaking is chiefly concerned with how individuals make sense of complex social dynamic environments and phenomena, construct mental representations of these phenomena, and use these representations to guide their action. In contrast to the more normative decision-making perspective that focuses on one-time decisions, such as choice of a therapy [21], and the problem-solving perspective that is concerned with overcoming barriers to achievement of self-management goals [22], sensemaking is about organizing the chaos of lived experiences, finding patterns, discovering connections and dependencies, and making a myriad of daily choices in regards to essential self-management activities. We propose that adopting a sensemaking perspective provides a new analytical lens for viewing self-management of chronic diseases that can enrich the existing scholarship and suggest new directions for research and for the design of technological interventions. The framework proposed here is grounded in existing scholarship on sensemaking and upon our experience designing, developing, and evaluating technologies for diabetes self-management [23–25]. To empirically validate the framework we reviewed and synthesized findings of qualitative studies of diabetes self-management practices published in peer-reviewed journals from 2000 to 2015. The review provided ample empirical evidence for the proposed framework; however, it also suggested a number of barriers to engaging in sensemaking. We use the proposed framework to outline the directions for the design of informatics interventions for facilitating diabetes self-management. Although diabetes is used as the exemplar disease, the model is generalizable to other chronic diseases.

2. Theoretical foundations for health self-management informatics

Over the years, researchers in biomedical informatics adopted a number of theories of health behaviors to the design of informatics interventions for health in wellness [17]. In this section we briefly review the more prominent theories; however, this list is far from exhaustive.

2.1. Social cognitive theory

Social Cognitive Theory (SCT) is most commonly associated with the works of Albert Bandura and is chiefly concerned with different motivators of human behaviors, and, particularly, with the role of social factors in shaping individuals' actions [12,13]. In the classic Bobo doll experiment, Bandura demonstrated that observing behaviors of others and outcomes of these behaviors (in terms of reward or punishment) has a profound impact on individuals' own choices.

According to SCT, individuals' behaviors are regulated by several critical human capabilities: (1) symbolizing capability – individuals' ability to rely on symbolic representations to comprehend their environment; (2) self-regulation – the ability to set goals and assess progress towards these goals, (3) self-reflection – the ability to critically examine one's own actions in light of one's standards and values; and (4) vicarious capability – the ability to learn by observing behaviors of others and consequences of these behaviors. SCT argues for the importance of cognitive processes and advocates for human agency in deliberately selecting responses to environmental stimuli, rather than blindly responding to them following a set of internal rules. According to Bandura: "People gain understanding of causal relationships and expand their knowledge by operating symbolically on the wealth of information derived from personal and vicarious experiences. They generate solutions to problems, evaluate their likely outcomes, and pick suitable options without having to go through a laborious behavioral search." [13]

Self-efficacy, an important concept within SCT, is concerned with individuals' beliefs in their own abilities to "exert control over their level of functioning and events that affect their lives." An individual's level of self-efficacy influences individuals' ability to set goals and pursue these goals in light of difficulties and overcome obstacles to goal accomplishment [13].

To date, SCT has been extensively used in the context of behavior change informatics interventions, particularly for smoking cessation (e.g. [26,27]) and weight-loss (e.g. [28,29]). The review by Riley et al. concluded that the theory appeared to have the most influence on the content of text messages used by the interventions, in particular in helping the participants to manage urges and to facilitate social support [17]. Further, Brendryen et al. reported using SCT in articulating the four sources of self-efficacy that can suggest specific targets for interventions [26].

2.2. Self-determination theory

Self-Determination Theory (SDT) is generally associated with the works of Richard Ryan and Edward Deci [14]. Similarly to SCT, Self-Determination Theory is chiefly concerned with humans' inner resources in regulating individuals' behaviors. According to Ryan and Deci, the main arena of SDT is "the investigation of people's inherent growth tendencies and innate psychological needs that are the basis for their self-motivation and personality integration, as well as for the conditions that foster those positive processes." SDT proposes that there exists a continuum in regards to the extent of the autonomy of individuals' regulation of their behavior, and the degree to which this behavior is driven by intrinsic (as opposed to extrinsic) motivation. More autonomous style of self-regulation and a higher degree of intrinsic motivation lead to superior performance, higher degree of learning, and a more positive coping style [14].

SDT identifies three psychological needs as driving factors for self-motivation. These include: (1) the need for competence – perception of self as possessing the skills and knowledge to perform the task at hand, (2) the need for relatedness – positive social engagement with others, such as teachers or caregivers, and (3) the need for autonomy – the perception of self as a driving force behind one's choices and actions. SDT posits that when these three needs are met with favorable social and environmental situations, individuals' intrinsic motivation flourishes; however, when they are suppressed, intrinsic motivation is often thwarted. One of the conclusions in SDT is that introduction of external rewards

contingent on task performance has a detrimental impact on intrinsic motivation [30].

An important concept that runs through both Social Cognitive Theory and Self-Determination Theory is that of self-regulation. In SCT, self-regulation is characterized as an individual's ability to work towards pursuing personal goals and to assess their progress towards these goals. Similarly, in SDT, self-regulation refers to individuals' ability to process and internalize extrinsic motivating factors and to use these factors to drive one's behaviors. For example, Ryan and Deci distinguish between four different types of extrinsic motivation and associated regulatory style from the least autonomous external regulation, to integrated regulation in which external motivating factors become completely congruent with an individual's own goals and values [14].

Informatics applications founded on the principles of SDT have focused on fostering individuals' intrinsic motivation for example in the context of adherence to medication and blood pressure monitoring [31], and in promoting an individual's sense of autonomy by helping them to focus on their own reasons for increasing levels of physical activity and exercise [32].

2.3. Theory of planned behavior

The Theory of Planned Behavior (TPB) is concerned with the relationship between intentions and behaviors and the different factors that may lead to individuals following through on their intentions and achieving desired behaviors or failing to do so [15]. According to TPB, three different independent factors contribute the pathway between intention and action. These include (1) the intention to act – a degree to which an individual favors a particular behavior; (2) the subjective norm – perceived social pressures to engage or not engage in the behavior; and (3) perceived behavioral control – an individual's perception regarding the ease or difficulty of engaging in the behavior based on their previous experience. This last notion of perceived behavioral control is similar to the concept of self-efficacy put forward within the Social Cognitive Theory that addresses an individual's level of confidence in their ability to perform desired behaviors and accomplish set goals. TPB specifically addresses volitional behaviors, in which individuals have a choice of whether to engage in the behavior or not.

Of relevance to this discussion is the treatment of past behaviors and habit in the context of TPB. According to Ajzen, past behaviors or records of past behaviors have bearing on future behaviors only indirectly, and in as much as they contribute to formation of intentions and perceptions of control, and to the development of habit [15]. Habit, however, when reliably measured could play an important role in influencing future behaviors.

Over the years, TPB has inspired multiple behavior change interventions that specifically focus on helping individuals to formulate intentions for improving their health behaviors, raise awareness of the social norms in regards to these behaviors, and help them to gain higher level of perceived behavioral control. Based on a meta-analysis of TPB-based interventions, attitudes, subjective norms, and perceived behavioral control account for 39% of the variance in intention, and for 27% of variance in behavior, when examining a wide range of health behaviors [33].

In the context of informatics interventions, TPB has been primarily utilized as a foundation for composition of messages that were delivered either through email or SMS (e.g. [34,35]). For example, Kothe et al. successfully used TPB constructs to help students enrolled in the nutritional program formulate intentions to consume more fruits and vegetables [35]. However, the application of TPB for self-monitoring and self-management technologies has been limited.

2.4. Transtheoretical model

Transtheoretical Model of behavior change (TTM) argues that behavior change is a process that can be described as an individual's progress along several steps, or stages of change [16]. These stages include: (1) precontemplation, in which individuals do not perceive a need for change and have no intention of changing their behaviors, (2) contemplation, in which individuals recognize limitations of their current behaviors and begin to explore alternatives; (3) preparation, in which individuals formulate intentions to take action, and may make small steps towards this action; (4) action, in which individuals implement specific steps towards adopting what they perceive as healthier behaviors, (5) maintenance, in which individuals have persevered in their new behaviors for 6 months and work on preventing relapse, and (6) termination, in which new behaviors became deeply embedded into individuals routine practices and old habits no longer present temptations.

Prochaska and Prochaska suggest that there exist multiple reasons why people do not change their behaviors, and that these reasons may differ depending on the individual's stage of change [36]. For example, those in precontemplation stage cannot change their behaviors because often they do not perceive their current behaviors as problematic, and as a result have no reason or desire for change. In contrast, individuals in preparation stage may want to change their behaviors but have little knowledge as to what to change and how. Consequently, behavioral interventions to promote change should be tailored to an individual's current stage of readiness. For example, they could focus on raising awareness for individuals in precontemplation stage, and on addressing specific information needs for those in preparation stage.

TTM has been widely applied to the design of informatics interventions for health and chronic disease self-management. One common approach is assessing an individual's readiness to change their behaviors and tailoring the content of the messages to their own stage and associated challenges and needs [37,38].

2.5. Problem-solving perspective

In addition to the more general theories described above, problem-solving has emerged as a well-articulated and influential framework for conceptualizing diabetes self-management. Hill-Briggs proposed the problem-solving model to account for how individuals identify and overcome external barriers to adopting desired self-management behaviors [22]. There is a growing scholarship regarding the importance of problem-solving skills to chronic disease self-management in general and to diabetes management in particular [39,40]. Problem-solving in diabetes self-management is included as one of the essential self-management behaviors by the American Association of Diabetes Educators [41]. The problem-solving model has given rise to a number of behavioral and informatics interventions for diabetes self-management that were shown to lead to improvements in individuals' glycemic control and psychosocial outcomes [42–44].

The theories discussed above, along with several others provide rich explanatory framework for individual health behaviors and factors that motivate them, and establish a firm foundation for informatics interventions that focus on health behavior change. However, as previously argued by others [17], most of these theories do not account for the continuous influx of new data and information available to individuals, including data collected with self-monitoring devices. For example Riley et al. argued that many known theories of health behaviors provide only a static view of an individual, and do not allow for dynamic adaptation of the intervention to the changing circumstances of use [17]. As a solution, these authors suggested incorporating dynamic systems modeling

approach from control systems engineering to flexibly adjust the content and dose of an intervention based on the changing context (individual and environmental). While this solution does account for the dynamic nature of human health behaviors and attitudes, it is more concerned with adapting interventions rather than with enabling human reasoning, sensemaking, and action.

3. The sensemaking perspective

Sensemaking has diverse theoretical routes and has been explored in a wide variety of domains and disciplines. Below we review perspectives on sensemaking from three different areas of inquiry where this perspective has become particularly influential: organizational behavior, education, and human–computer interaction.

3.1. Sensemaking in organizations

One of the earliest accounts of sensemaking was proposed by Carl Weick who conceptualized sensemaking as a process through which individuals make sense of complex social dynamic situations to construct their own roles and stories within their organizations [45].

According to Weick, first of all *sensemaking organizes flux*: when individuals are confronted with situations that challenge their sense of meaning or do not fall into their existing set of action scripts, the flow of routine activities is interrupted. *Sensemaking is about noticing and bracketing*: individuals examine the situation at hand trying to classify it in relation to their existing mental models of related phenomena. *Sensemaking is about labeling*: individuals give shape to their lived experiences through verbal description. Labeling allows individuals to share their meanings with each other and contributes to the development of common ground [46]. *Sensemaking is retrospective:* individuals construct meaning of situations only after they have completed their involvement and can reflect on the outcomes. *Sensemaking is about presumption:* engaging in sensemaking requires the ability to not only reflect and examine, but also to act upon concrete situations and adopt a plausible hypothesis. *Sensemaking is social and systemic: an* individual's sensemaking is shaped by and, in turn, shapes the opinions of others. Organizations provide social structures in which meanings are formed, and are shaped by these emerging meanings. *Sensemaking is about action* and often begins with a situation when individuals encounter a barrier to routine action. Finally, *sensemaking is about organizing through communication* and is carried out through informal discussion where meaning is not only shared but is also actively constructed by the participants. Here Weick draws an analogy between sensemaking and articulation, a "social process by which tacit knowledge is made more explicit and usable." [47] In fact, the articulation and sensemaking of individuals is what gives shape and structure to organizations.

Weick's characterization of sensemaking is informed not only by observations of normal organizational functioning, but also by its dramatic failures. For example, during the Mann Gulch (Montana) disaster, 13 smokejumpers were burned in a wildfire [48]. In contrast to the more traditional characterization of this situation as a failure of decision-making, Weick suggested that the disaster was precipitated by the smokejumpers' inability to correctly construct the true meaning of the situation and their role in it. Weick proposed that the smokejumpers were trying but failing to fit the reality of the fire to their classification of it (as a "10:00 fire" – fire that can be overcome by 10:00 the next day). As a result of this disconnect, their actions, while appropriate for the 10:00 fire, did not fit the reality of the situation, thereby leading to disastrous consequences. Despite some obvious differences, Weick draws parallels between the small smokejumper crew and organizations, and builds a case for sensemaking failures as a root cause of many problems within organizations.

Application of Weick's sensemaking framework extends beyond organizational behavior. For example, Weick illustrated properties of sensemaking using a retrospective account of a pediatric critical care nurse making sense of dramatic changes in patient status observed within a 2-h time-frame [49]. Similar to the Mann Gulch situation, other members of the patient care team did not witness the changes first hand and continued to perceive the patient as stable. However, in contrast with the Mann Gulch situation, the nurse was able to draw on shared experiences and common ground between clinicians to re-orient them to the new reality.

3.2. Sensemaking in education

Sensemaking perspective in education has largely focused on science education and on the contrast between scientific and everyday thinking. The traditional view of science education draws a strict contrast between scientific thinking, characterized by rationality, precision, formality, detachment, and objectivity, and everyday thinking, characterized by improvisation, ambiguity, informality, engagement, and subjectivity [19]. In the traditional perspective, everyday lived experiences and language are often perceived as incongruent with scientific thinking and as a source of educational problems. In contrast to this view, proponents of the sensemaking perspective in education argue that the kind of improvisational thinking and learning that happens in the context of mundane everyday life, which contrasts with how science is taught in schools, has many stark similarities with how science is actually practiced by scientists [50,51]. For example, Saxe examined everyday math abilities of largely unschooled Brazilian youth street vendors who nonetheless were able to perform sophisticated mathematical operations, such as calculating prices and dealing with currency and change, in the context of their daily practice [52]. Similarly, Warren et al. studied how minority children whose native language, Haitian Creole, is considered inferior to English in its ability to support scientific discourse, constructed complex scientific concepts such as "grow" (defined as gradual change) and "develop" (defined as abrupt transformation) through participating in class discussions [19].

In addition, the sensemaking perspective takes a different view on the process through which learning, and in particular, experimental learning is accomplished. Traditional scientific learning favors logical, hypotheticodeductive reasoning in which individuals search through a space of available alternatives until a hypothesis is formulated and attempt to validate it with experimentation [53]. In contrast to this view, Warren et al. found that children who participated in their studies were not as much defining variables as actively constructing them, for example, refining the scientific definition of the term "darkness" by imagining themselves inside their experimental world and the different ways to experience darkness.

3.3. Sensemaking in human–computer interaction

The proliferation of personal computing in the late 80s and early 90s led to a dramatic increase in information available to both professional analysts and lay individuals searching for and viewing information from their home computers. Russell et al. were among the first to introduce sensemaking into the Human–Computer Interaction (HCI) community [54] by examining the efforts of expert analysts when creating a formal knowledge representation of a particular domain. In this tradition, sensemaking is defined as "the way people go about their process of collecting,

organizing and creating representations of complex information sets, all centered around some problem they need to understand." [54].

While the majority of early HCI sensemaking studies focused on professional analysts, more recent scholarship has shifted its focus towards everyday non-expert thinking. For example, DiMicco et al. [55] proposed that sensemaking is a common activity on Social Networking Sites where individuals interpret multiple profiles of others in order to recreate their image. Similarly, many studies examined Wikipedia as a digital environment for collective sensemaking where individual authors negotiate their opinions and collectively construct a narrative reflecting their shared knowledge on the topic of interest [56].

Over the years, HCI researchers proposed a variety of tools for facilitating sensemaking. For example, Billman et al. described a digital environment for professional sensemaking where analysts can review, annotate, and cluster information, elaborate their inferences and conclusions, and share them with others [57]. Wu et al. used geo-visualizations, such as coordinated maps and activity visualizations to aid sensemaking in emergency situations [58]. Paul et al. proposed ways to facilitate collaborative sensemaking and information seeking online with tools that help individuals monitor each other's sensemaking activities and share results [59].

3.4. Other relevant perspectives

In addition to these rich characterizations of the sensemaking process, other accounts of sensemaking or similar phenomena exist. For example, Park's meaning-making perspective is chiefly concerned with how individuals construct meaning, particularly in regards to stressful and disruptive situations in their lives [60]. In meaning-making, individuals possess a global orienting system, which helps them to make sense and understand various phenomena and situations in their lives. When encountering situations that cannot be explained from their existing orienting system, individuals must appraise their new experiences and adjust their orienting system to "restore the sense of the world as meaningful and their own life as worth-while" (Park, p. 258). In communication and knowledge management, Dervin's Sense Making approach is chiefly focused with knowledge creation and management and the ways individuals find structure in the flux of everyday experiences [61]. According to Dervin, individuals engage in sensemaking as essential gap-bridging behaviors when continuity of their experience is interrupted by gaps in understanding. In this context, knowledge and information are constructed not as ends in themselves, but as part of bridge-building activities that allow individuals to close gaps.

3.5. Sensemaking framework in diabetes self-management

Individuals diagnosed with a chronic disease such as diabetes are often thrown into an unfamiliar world with only a surface understanding of the underlying dynamics of the disease and the impact of daily activities on their health. Specifically, in the case of diabetes, individuals must re-examine such mundane everyday activities as grocery shopping, cooking and eating meals or participating in social gatherings, and adjust their practices to the new demands of diabetes self-management. Consequently, they experience frequent and multiple gaps in their understanding and their ability to select appropriate action, and must make sense of the new situation in order to construct their new reality. The notion of gap is critical to our view of sensemaking and is consistent with theoretical perspectives of Weick [18] and Dervin [61].

We propose that self-management activities can be carried out in one of two modes: ***sensemaking mode*** and ***habitual mode***. We characterize the ***sensemaking mode*** of functioning as explicit and effortful, in which individuals analytically engage with a situation at hand, examine its different properties, and construct explanations that allow them to select appropriate action. We contrast it with a more implicit and passive ***habitual mode***, in which new experiences do not create gaps in understanding. The habitual mode allows an individual to utilize preexisting mental models that reflect their lifetime experiences shaped by psychological, social, cultural, and economic factors. While the sensemaking mode leads to new discoveries, the associated effort can also lead to burnout [62]. As a result, individuals engage in sensemaking to address gaps and build bridges, and return to the habitual mode once continuity in their understanding is restored.

Further, we propose that both habitual and sensemaking modes in diabetes self-management involve three essential activities (see Fig. 1): (1) *Perception*: monitoring and classification of new information and experiences related to an individual's health and wellness; (2) *Inference*: development and activation of relevant internal representations that allow individuals to select an appropriate course of action; and (3) *Action*: the process of carrying out daily activities in response to the new information.

As individuals encounter new information and experiences, they quickly assess them for fit with their existing understanding of the world. When perceptions do not create gaps in understanding, individuals operate in the habitual mode that requires minimal inference and leads to routine action. However, if new experiences do not fit preexisting models, individuals engage in more active sensemaking. In these situations, individuals first identify and examine salient properties of the new situation and then draw on their ***general knowledge, knowledge of others*** and their own ***past experiences*** to construct a plausible explanation that can suggest future action. Finally, in sensemaking mode routine action is replaced with purposeful and deliberate experimentation in which individuals actively examine newly constructed inferences and explanations and test their validity.

While the sensemaking process has pattern and organization, sensemaking activities are rarely distinct and sequential. More often they overlap and interact, rendering sensemaking as an ongoing, improvisational, informal activity where new explanations are constructed and dismissed and operational mental models are continuously redefined to incorporate the continuous influx of new experiences.

3.5.1. Sensemaking mode

3.5.1.1. Perception. At diagnosis, individuals with diabetes are usually instructed to monitor and maintain blood glucose levels within target ranges, and to adopt healthy eating and daily exercise as lifestyle behaviors. These new activities create a new stream of information that individuals need to process and incorporate into their action, and often lead to gaps in understanding. For example, when faced with undesirably high or low blood glucose readings, individuals try to construct explanations that can suggest what changes are necessary to maintain glycemic control. An individual who participated in one of our previous studies explained it this way: *"...you see a high number and the first thing that goes through your mind is "dude what did I eat that was wrong?"...Or "how much did I eat that was wrong?" (P1, [24]).* This process has many similarities with Weick's account of sensemaking in organizations [18]. In both situations, the process is triggered by a gap in understanding and inability to proceed with usual action. In both situations, individuals characterize and classify their observations using preexisting mental models and either match them to an existing structure or identify them as unique thus requiring a new explanation.

In our own studies we found that unexpectedly high blood glucose readings presented the most opportune moments to engage individuals in analytical thinking, and share many properties with

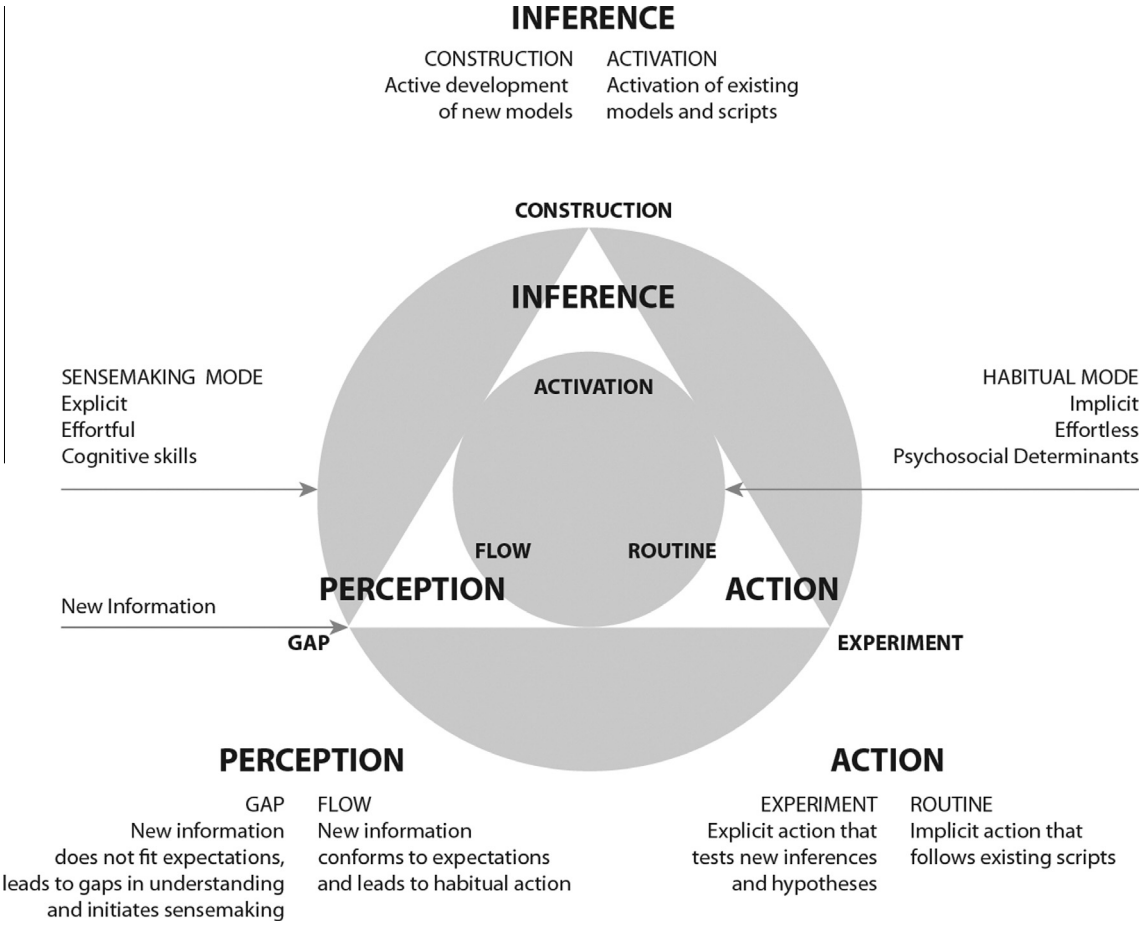

Fig. 1. Sensemaking framework for chronic disease self-management.

"teachable moments" [63]. Such gaps in understanding, however, can arise in any situation when individuals' regular activities do not lead to expected results and need deliberate examination.

3.5.1.2. Inference. When faced with gaps in understanding, individuals engage in explicit, analytical, and effortful sensemaking that necessitates construction of new inferences and adjustments to the existing models. This often involves examination of the existing disease-related knowledge, as well as reflection on one's own past experiences and search for similarities and possible clues as to the current situation. For example, when faced with an undesirably high blood glucose reading, individuals may reflect on their activities prior to the reading, and think whether and how these activities contributed to the rise in blood glucose. Alternatively, they may think about previous cases when they had high readings and whether there were any similarities in the activities leading up to these readings. These processes are akin to case-based reasoning, whereby individuals rely on specific instances of previous experiences [64] or schema-based reasoning, in which individuals rely on generalized schemas that integrate multiple instances [65]. As a result of these reflections, individuals may generate a plausible explanation, such as "Chinese food leads to spikes in my blood glucose levels" and use that explanation to guide future choices. Notably, this process is less structured and systematic compared to the more traditional decision-making paradigm, and more emergent and fluid as would be expected within sensemaking, with the constructed explanation continuously revised as new information is received and considered [19].

During inference, individuals often activate their social networks and look to others for insights regarding possible explanations, thus creating opportunities for facilitated sensemaking [66] and shared mind [67]. However, in contrast to the inherently social organizational sensemaking, much of sensemaking in diabetes self-management occurs in isolation when individuals are limited to their own experiences and conclusions.

3.5.1.3. Action. As a result of these inferences, individuals select the most plausible explanation that allows them to resume action and integrate it within their operational model of diabetes self-management that becomes a basis for future action. The model stays operational until a new experience contradicts it requiring re-examination of inferences, and at times, redefinition of variables. Sometimes individuals actively experiment to test the hypothesis under different circumstances. Eventually, new actions become routines that are upheld until new observations and experiences challenge their current models and hypotheses.

3.5.2. Habitual mode

In contrast to the explicit and effortful sensemaking mode, habitual mode unfolds naturally without requiring explicit attention and effort. As such, habitual mode is a default state that individuals maintain and attempt to return to after engaging in sensemaking. During habitual mode, perception of new information does not create gaps in understanding, but rather enables flow of experience. On the inference phase, habitual mode does not require active construction of new mental structures, but rather

activation of the existing ones. Finally, in habitual mode, individuals fall onto their routine actions, rather than experimenting with new choices.

4. Empirical support for sensemaking in diabetes self-management

4.1. Method

In order to empirically evaluate the proposed model, we used an approach consistent with meta-synthesis method for summarizing published qualitative studies of diabetes self-management behaviors. Qualitative meta-synthesis has been proposed as a systematic approach to summarizing and synthesizing findings of qualitative research [68]. The common steps of meta-synthesis include: formulating research questions and rationale, searching for and retrieving published manuscripts describing qualitative studies, classifying the findings across studies, and synthesizing findings. In this study we followed similar steps; however, because our focus was on interrogating the proposed framework, we used selective theoretically-grounded coding approach based on the framework concepts.

4.1.1. Research questions and rationale

The main research questions that guided our selection of inclusion and exclusion criteria for the review were: (1) How do individuals with diabetes engage in self-management? (2) What factors serve as barriers and facilitators of self-management? and (3) What difficulties and challenges do they experience as part of self-management?

4.1.2. Search

The first author developed the search strategy using the following key words included in title and/or abstract: 'diabetes OR Diabetic OR People with diabetes OR Diabetic patients' AND 'self-management' AND 'qualitative OR grounded theory OR phenomenology*'. A librarian was consulted to customize search terms for different databases. Based on the study objectives, the manuscripts were selected based on the following inclusion criteria: (1) original research with the focus on patients' accounts of their approaches to self-management; (2) papers published by peer-reviewed journals; (3) research methods including qualitative methods, (4) full text is available in English, and (5) the manuscript is published between 2000 and 2015. The exclusion criteria included: (1) studies using quantitative methods only, (2) studies of self-management interventions with the main focus on individuals' attitudes towards the intervention, (3) studies of healthcare providers, and (4) studies with the exclusive focus on unique cultural needs of ethnic minorities. We did not exclude studies based on the type of diabetes (type 1, 2, and gestational were all included), and the age of the participants (including both adults and adolescents with diabetes). The databases searched included PubMed, MEDLINE, Cochrane Library, and PsycInfo (see Fig. 2).

4.1.3. Search results

The initial search returned 174 manuscripts. After the initial title and abstract review, 105 manuscripts were excluded because they were not related to the research questions. The first author carefully examined the full text of the remaining 65 articles; 15 manuscripts were excluded on this phase because they either did not include patient perspectives [2], focused on cultural differences of ethnic minority populations, rather than on self-management [5], focused on perspectives of healthcare professionals [5], or on patient-provider communication, rather than self-management [3]. The remaining 50 manuscripts were included in the review.

4.1.4. Classifying the findings

After examining results sections of the manuscripts included in the review, 369 individual findings were extracted; that included 171 themes, and their subthemes (all themes and sub-themes were reported by the authors of the reviewed reports rather than inferred by our research team). Because the purpose of this study was to interrogate the proposed framework, the researchers undertook a two-prong coding approach. First, an open coding approach was used to classify the findings into main categories and generate summaries of these categories. The detailed description of these categories is beyond the scope of this paper; we include a brief summary of major findings in Appendix A. In the second step, the researchers conducted selective coding of the findings paying attention to phenomena related to individual discovery, making sense of the disease and one's own approach to managing it, and dealing with uncertainty [69]. As a result, this coding was both, inductive and theoretically grounded.

4.2. Results

Overall, the majority of the reviewed manuscripts (43 out of 50) reported findings consistent with the proposed framework. The analysis identified the following major categories: (1) The need

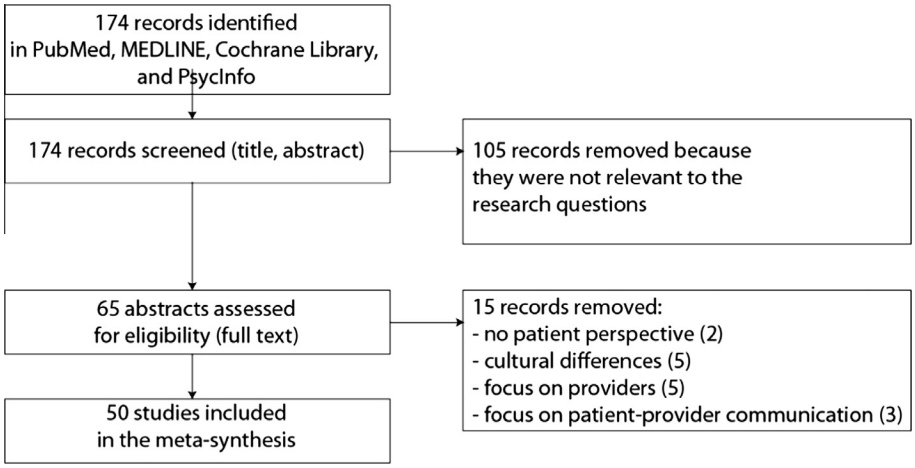

Fig. 2. Flow chart of literature search.

for individual discovery. (2) Sensemaking and habitual modes in diabetes self-management. (3) Perception – Inference – Action cycle; this included (a) Breakdowns as triggers for sensemaking. (b) From breakdowns to discoveries. (c) Translating discoveries into action. (4) Barriers to sensemaking. Below we discuss these findings in relation to the framework concepts.

4.2.1. The need for individual sensemaking and discovery

A persistent theme in the reviewed reports was the need for individuals to flexibly adjust self-management recommendations to their unique lifestyles. Many studies commented on the difficulty of translating general self-management guidelines (e.g. increasing intake of vegetables) into specific daily behaviors (e.g. what should I have for lunch today?) [70–72]. Studies painted diabetes self-management as a complex activity with high individual variability and intricate interrelationships between daily activities and blood glucose values [73–75,70,76,77]. Because self-management requires many changes to one's lifestyle, it can impact an individual's routines and schedule, ability to perform their job, and overall quality of life. Moreover, individuals' unique cultural [72,78], and economic [79] circumstances all require that the individuals adapt general self-management guidelines to their unique needs and priorities. Consequently, each individual needs to find a unique combination of self-management activities that are effective and sustainable in the long run.

Another common finding was that of balance, particularly between an individual's quality of life and the need to manage diabetes [80,73,81,82]. Making lifestyle changes such as eliminating favorite foods or activities can lead to feelings of depravation, depression and burnout and withdrawal from self-management [83,84]. Many studies suggested that individuals with diabetes often try to find a balance between a desired level of glycemic control and quality of life, preserving their most cherished routines and habits [85,83,72]. At times of strong conflict between quality of life and self-management, individuals knowingly deviated from the recommended behaviors and used various strategies to minimize the impact of these lapses on their blood glucose control [86,81].

All these observations suggest the importance of sensemaking and discovery in diabetes self-management and the need for a theoretically and empirically-grounded way of conceptualizing these processes.

4.2.2. Sensemaking and habitual modes in diabetes

In the proposed framework, we distinguish between explicit and effortful sensemaking mode, in which individuals analytically engage with the situations and examine their properties, and habitual mode, in which individuals follow their established patterns and routines. Several of the studies included in the review made a similar distinction. For example, Moser et al. differentiate between *daily self-management* (akin to the habitual mode), in which individuals follow their routines, and *off-course self-management* (akin to the sensemaking mode), in which individuals react to unusual circumstances, such as worsening of symptoms, an additional illness, or unusually high or low blood glucose readings [77]. Similarly, Paterson and Thorne distinguish between *decision-making in familiar situations*, when individuals quickly attribute changes in their blood glucose levels to familiar reasons and *decision-making in unfamiliar situations*, when individuals lack immediate explanations and have to proactively examine probable causes [87].

Moreover, many of the reviewed studies included findings consistent with our notion of habitual mode. In particular, many authors discussed absence of recognizable symptoms in diabetes as one of the main barriers to engaging in proactive self-management [88,89,85,90,91,84,92–94]. Without perceived symptoms, individuals did not experience any breakdowns in their routines and understanding, and continued their habitual activities. "Out of sight, out of mind" was a common way to describe individuals' attitudes [88].

In contrast, when participants of the studies experienced gaps in understanding, they actively sought new information and examined their past experiences to fill these gaps and enable action [95,77,96,84]. In the majority of cases, these gaps were related to such daily activities as choosing meals:

> "They (told) me that my blood sugar was far too high and ... told me to try and bring this down to a manageable level. I'm basically not eating because they're sorta saying you know, control it and what not and I was eating very little – eating enough to stay alive but eating very little – still blood sugar wouldn't come down." [84].

For those on insulin therapy, these gaps were often related to the need to adjust insulin dose:

> "I'm slightly unsure, you know, now I'm basically on my own and I've reduced the background insulin and it's slightly 'ooooh, I'm not sure I should be doing that." (F7.) [97].

4.2.3. Perception–inference–action cycle

The proposed framework suggests that sensemaking includes three essential activities: perception and classification of new information related to diabetes, accounting for this information using existing mental models or by creating new ones, and carrying out action consistent with individuals' explanatory frameworks. We found ample support for this view in the reviewed studies.

4.2.3.1. Breakdowns as triggers for sensemaking. Similarly to our own studies of diabetes self-management [23,24], the notion of breakdowns and gaps in understanding was ubiquitous to many papers included in the review [96,90,98,95,99,77,100,94]. Often, these breakdowns were related to unexplainably high or low blood glucose readings that the participants were confronted with:

> "When you see your blood sugar is within normal range, then you don't feel anything. If it is going up then you have to start thinking, what is wrong – the type of food I'm eating yesterday or the day before – that it is not up to the mark, or I've taken some more type of carbohydrate." [90]
>
> "... in the morning it is 120. If I drink or have any bread it goes up to '2-something' real fast. I ask, I ask why does it go up so high? I don't understand that." [P No. 5: African-American female] [91].

4.2.3.2. From breakdowns to discoveries. After experiencing a breakdown, the participants of many of the studies engaged in active examination of their past experiences of relevance to the current situation looking for similarities and patterns. The description of such personal discovery process was present in the many studies in the review [88,101,102,74,103,81,104–107,71,98,77,108,82] Several authors described this mode of learning as *experiential learning* and suggested that it is more effective than the more traditional learning from experts [101,87].

> "The experiential learning method is more effective, for instance, having a breakfast and exercise meeting where patients can experience diet-related or exercise-related changes in their blood glucose level." [Group E1, diabetes educator 2] [101].

Paterson and Thorne provided a detailed account of the inference-development approach they observed with individuals trying to construct explanations for unexpectedly high blood glucose readings. Consistently with the sensemaking view, the authors suggested that instead of following a hypotheticodeductive approach and formulating and testing a single hypothesis [87], individuals actively constructed variables, developed multiple different hypotheses, and used such cognitive strategies as anchoring and adjustment, and reasoning backwards to determine which hypotheses presented a better fit with the available evidence [87]. Burda et al. describe how individuals with diabetes in their studies used daily curves to construct explanations for daily fluctuations in their blood glucose readings:

> "It's a good idea to make such a day curve before you consult your doctor. That offers you a general idea of your blood glucose levels, and you get to know your body's reactions in different situations." (Quote from F.G.) [103]

This construction process was particularly apparent in the studies of individuals using flexible intensive insulin treatment, a regiment that allows individuals to flexibly adjust their doses of insulin based on their current BG levels and their anticipated activities. Ranking et al. describe this process as "playing around" to find the optimal approaches to adjusting insulin though trial and error while continuously adjusting their mental models of how insulin impacts blood glucose [97].

Once individuals formulated an initial hypothesis in regards to the plausible explanations, they often sought the help of their healthcare providers [88], or activated their social networks [104] to assess feasibility of their accounts and to seek relevant experiences of others.

> "And then I thought; enlist so you can meet people in a similar situation, and then you can meet someone who is worse off than you are. Chat with them and get some good advice, it could be helpful for me and my work, so I decided to enroll." (Woman, age 46, diagnosed 6 years ago). [104]

One of the manuscripts included in this review not only reported on findings consistent with the proposed framework, but also suggested ways to conceptualize how individuals learn and make new discoveries in the context of diabetes self-management. Moser et al. described the following steps involved in what they defined as "off-course self-management": (1) becoming aware of unusual patterns, (2) reasoning about the causes of irregularities, (3) deciding on the probable causes and the course of action, (4) taking specific action to resolve the off-course event, and (5) evaluating effect of their actions [77]. This account is consistent with the proposed framework, thus further establishing its plausibility and applicability to diabetes self-management.

4.2.3.3. Translating discoveries into action. Sensemaking scholars argue that the ultimate reason for engaging in sensemaking is in driving an individual's action [100,94,82]. The studies included in the review are consistent with this position and with the proposed framework in that they describe informing action as the ultimate goal of experiential learning:

> "Okay, as a result you need to do. . .or. . .something that you should be considering or following as a result of what your sugars are. . ."[106]

In lieu of this clear goal, self-monitoring of blood glucose levels becomes a "spectator" activity, with unclear benefits:

> "Spectator testing – just testing to watch the numbers go up and go down is a waste of time, of money, and of a drop of blood." (Supa) [88]

To test new inferences, the participants of the studies often engaged in active experimentation testing the impact of different choices on their blood glucose levels:

> "I eat something, I count the carbs, then test and see if my BG level goes over my target. If it does I reduce my carbs (cut the portion size or replace it with an alternative) for that meal." (Grady) [88]

Once the positive impact of a new activity has been established, the new inferences were often incorporated into the operational arsenal of individuals' self-management strategies, and new actions became habits:

> "The best is that it [new diet and increased level of physical exercise] is not something that I'm aware of anymore. It has become a habit. . . a healthy habit." (Male, 60–69 years, diagnosed four years ago). [88]

4.2.4. Barriers to sensemaking

However, together with the support for the proposed framework, the studies included in the review suggested a number of potential barriers to engaging in sensemaking reported by the authors of the reviewed studies.

For example, several authors described frustration experienced by individuals with diabetes who had to overcome skepticism and lack of support from their healthcare providers [87,75]:

> "When you try to adopt a proactive approach to management of (diabetes) you have to fight tooth and nail to get what you want". (Peru) [88]

Some participants were discouraged from frequently checking their blood glucose level, by their healthcare providers:

> "Well putting it mildly the nurse recently told me off. . .. She had a right old go at me asking who told you that you should self-test? I told you, you only test if your on Insulin. . . you'll make a mess of your fingers, anyone who tells you to test is WRONG. . . I usually keep so positive but I feel as if I just can't be bothered anymore." (Virginia) [85]

This lack of support, which often led to inability to purchase and reimburse testing strips, created the perceptions of loss of control and disempowerment among the participants:

> "Since my strips were stopped I have been feeling really down. . .. It feels like they are snubbing me for controlling my blood glucose so well. I am totally gutted and worried what to do next." (Stokeblock) [88]

Similarly, several studies reported that while older adults participating in their studies perceived experiential knowledge as a positive concept, diabetes educators thought more negatively about it [101,109].

5. Discussion

In this paper we argue that sensemaking and discovery are critical activities in diabetes self-management and propose a theoretical framework of sensemaking in diabetes informed by theories of sensemaking in organizational behavior, education, and HCI. Our review of qualitative studies of diabetes self-management practices provides ample evidence in support of the framework and suggests that the concepts we propose here are consistent with observations of other researchers.

However, the literature review also suggested that while the phenomena we discuss are well familiar to the research community, the language for describing this phenomena and ways to

conceptualize it have not been sufficiently explored. There was little consistency among the included studies in their characterization of individuals' experiences, varying from experiential learning, to decision-making, to problem-solving, among others. While many researchers discussed the need to flexibly adjust and adapt each individual's self-management practices to their unique personal values and preferences, and their cultural, social, and economic circumstances, few suggested sensemaking and discovery as means to achieving these goals. Moreover, several studies uncovered a high degree of skepticism towards experiential learning among healthcare professionals. This suggests a need for an open discussion within medical and informatics communities about an individual's role in monitoring and managing their health.

The proposed model has several tangible benefits that can inform future research in biomedical informatics and in the design of data-driven informatics interventions for sensemaking and discovery. Specifically, the model suggests that there are a number of preconditions that need to be met to enable individuals to move through the sensemaking process. When these preconditions are not met, sensemaking stagnates and mental models continue to have unresolved gaps often preventing individuals from making changes to their action, and at times from taking action at all. At the same time, the model suggests new directions for interventions that can enable preconditions and thereby facilitate sensemaking.

First, our model identifies gaps in understanding as the first precondition to and trigger for sensemaking. In diseases such as diabetes, where the feedback loop between actions and changes in health conditions is tight and can be observed within a short timeframe, each new observation can trigger the sensemaking process. Other chronic conditions, such as cancer, lack immediate and easily captured indicators, which may considerably slow down individuals' sensemaking. Even in diabetes, infrequent monitoring of blood glucose may obscure identification of problematic blood glucose patterns and create a false impression of continuity in understanding. This highlights the potential for self-monitoring technologies to serve as a catalyst to gaps in understanding by highlighting abnormalities and deviations in the captured data, and suggesting opportunities for additional data collection when necessary, as is common for diabetes education programs that focus on individual discovery.

Second, once individuals recognize discrepancies between their expectations and observations, they search their memory and available knowledge for related experiences to enable classification and inference. There is a considerable body of research examining human memory that highlights its constraints and limitations [110]. As a result, individuals may fail to see connections between their new observations and past experiences or fail to integrate the new discoveries within their existing model. If every new observation is viewed as unique, an individual's perception of the disease will merely be a collection of disjointed facts rather than a comprehensive mental model where experiences are connected together in a series of inferences and explanations. Here, new tools can help individuals to not only review relevant records from the past, but to also identify possible patterns and correlations. Many current self-monitoring applications provide their users with visualizations of captured data. The next step for sensemaking interventions would be to include tools for active manipulation and analysis of these data. For example, these interventions may enable users to search for occurrences of specific events (e.g. show me my 2-h post-meal blood glucose level every time I had pizza) or compare different events (e.g. show me my average change in blood glucose from pre-meal to 2-h post-meal after eating pizza as compared to after a salad).

Finally, once new connections are suspected, they need to be validated. Many self-management applications allow users to set behavioral goals, for example, in regards to diet, or exercise. However, few enable individuals to track the impact of their behavioral goals on health outcomes of interest. Here, new technologies informed by the sensemaking perspective could help individuals to not only set specific goals, but also track the impact of these goals on various indicators of health.

6. Limitations

This work has a number of limitations. First, while the authors attempted to include a comprehensive set of search terms, it is possible that relevant empirical studies were not included in the final review. However, the number of manuscripts included in this review far exceeds numbers included in the recent relevant meta-syntheses; for example a meta-synthesis of diabetes self-management practices by Stiffler et al. included 21 studies [111], and a meta-synthesis of self-monitoring practices by Chen et al. included 7 studies [7]. In addition, metasynthesis, as other qualitative analysis methods, is interpretive in nature; it is possible that the authors' interpretations of findings are different than the original interpretations of the authors of the manuscripts included in the review. However, the major limitation of this work is that the proposed framework has not been validated on its ability to inform the design of informatics interventions for chronic disease self-management. It is our hope, however, that if successful, this framework can lead to a new body of work in health informatics, which will test and enrich its constructs.

7. Conclusions

Our interest regarding the relevance of sensemaking in chronic disease self-management was inspired by our experiences designing, developing, and evaluating informatics interventions for diabetes self-management and qualitative studies of individuals' engagement with these interventions in the context of their daily lives. The proposed framework for sensemaking in chronic disease self-management is specifically based on diabetes but is generalizable to other chronic diseases that require self-monitoring. The framework suggests that sensemaking involves three essential inter-dependent activities: perception of new information and experience, development of inferences on these perceptions, and using these inferences to guide action. The proposed model is inspired by rich scholarship on sensemaking within organizational behavior, education, and human computer interaction and is consistent with existing literature on self-management in diabetes and its barriers. The framework suggests new directions for research in interventions for facilitating self-management in diabetes.

Contributors

There are no collaborators beyond the co-authors of the paper.

Conflict of interest

The authors have no competing interests for this publication.

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Appendix A. Supplementary material

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.jbi.2015.06.006.

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